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ABSTRACT

This study examined dynamics of families with handicapped children by focusing on the emotional, intellectual, and behavioral manner in which the undiagnosed siblings experience the diagnosis and existence of a brother's or sister's handicap within the context of their families. Subjects were 8 socioeconomically middle class families consisting of an intact marital dyad; a diagnosed child between the ages of 6 and 18 who was enrolled in school; and between one and three undiagnosed siblings, at least one of whom was age 12 or older. Participating members included 16 parents, 1 grandfather, 8 diagnosed children, and 14 undiagnosed siblings. Handicaps of diagnosed siblings included autism, Down's syndrome, Tourette's syndrome, learning disabilities, juvenile rheumatoid arthritis, spina bifida, and blindness. Data collection consisted of direct observations and intensive interviews. The data analysis identified15 patterns among the families and revealed 12 unanticipated insights. Among these insights were the findings that: (1) undiagnosed siblings emphasized the normal aspects of their handicapped sibling more than the parents did; (2) the later in the disabled child's development that the diagnosis was made, the more devastating appeared to be its effects on family members' adjustment; and (3) undiagnosed siblings were often curious enough about their sibling's handicap to undertake personal research about it. Data also revealed that in no case had a professional person interacted or communicated with an undiagnosed sibling at any length. Fathers' needs for information and communication about how to care for their handicapped child seemed to have been overlooked by professionals as well. These findings have implications for both research and practice. (NB)

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The Forgotten Children - Siblings of the Handicapped: A Family Systems Perspective

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Abstract

In this study, consideration is given io the transactional nature of relationships within "handicapped" families , defined as families that include a diagnosed child. The primary focus is on the myriad factors that appear to impact on undiagnosed siblings as they strive to meet the special challenges that a diagnosed child presents to their overall family life, their individual development, and their hopes for the future.

Dewey (1915) purported that the restoration of a sense of community might provide motivation for individual growth. With a fuller understanding of the meaning of a connected individual, insight might be derived that would promote a systems perspective in working with a sibling who has a brother or sister who is diagnosed as handicapped. Thus, the purpose of this study is to better understand the dynamics of families with children who are identified as handicapped. The specific focus, however, is on the emotional, intellectual, and behavioral manner in which the undiagnosed siblings experience the diagnosis and existence of a brother's or sister's handicap within the context of their families.

The selection process, the subjects, and the procedure

Handicapped families were identified through contacts made by the primary researcher with numerous agencies, schools, and former colleagues. The selection process involved controlling for the following similarities:

1. an intact marital dyad,
2. a diagnosed child enrolled in school and at least one undiagnosed sibling who together resided in the home of their parents,
3. the diagnosed child was between the ages of 6 and 18,
4. the number of undiagnosed siblings in each family did not exceed 3,
5. all families were considered by the contact source to be socioeconomically middle class, and
6. at least one undiagnosed sibling in each family is 12 years or older (this was decided after the selection of three families)

The study group consisted of eight handicapped families, defined as families which include a diagnosed child. The operational definition of what constitutes a diagnosed child is that a child is handicapped if both the family and a relevant child agency so define the child. The participating family members included sixteen parents--eight fathers and eight mothers, one grandfather, eight diagnosed children, and fourteen undiagnosed children. The diagnosed child population included five boys and three girls who ranged in age from 7 to 17. Within the undiagnosed child population, there were nine girls and five boys who ranged in age from 5 to 27. Handicaps varied and included diagnoses of autism, Down's syndrome, Tourette's disorder, learning disabilities, attention deficit disorder, juvenile rheumatoid arthritis, spina bifida, and blindness. Names of families have been changed for the purposes of anonymity. Table 1 describes the families.

TABLE 1
Family Demographics

Family #	Undiagnosed Siblings	Diagnosed Siblings	Mothers & Fathers Ages & Occupations
1. Strong	Jason, now 6	Jeremy, now 10 Autism, *age 5	Jo, 40, Dietitian Sam, 42, Engineer
2. Hope	Ellen, now 5	Melody, now 7 Down's syndrome *At birth	Lily, 33, Med Tech Bill, 35, Technician
3. Wright	David, now 14	Daniel, now 17 L. D. & A.D.D. *6th grade	Margaret, 45, Volunteer George, 45, Real Estate
4. Reasoner	Susie, now 13 Sandy, now 13	Johnny, now 10 Tourette's & A.D.D., *4th grade	Janella, 36, Finisher Peter, 39, Engineer
5. Edge	Jared, now 18 Wally, now 16 Amanda, now 14	Charmaine, now 7 Juvenile Rheumatoid Arthritis, *18 months	Sally, 35, Clerk Dennis, 35, Millwright
6. Valor	Jennie, now 18	Bridget, now 15 Spina Bifida *At birth	Ruth, 42, Bookkeeper Ken, 44, Machinist
7. Shepherd	Paul, now 27 Rebecca, now 24 Rachel, now 18	Theo, now 13 Down's syndrome *At birth	Mary, 55, Retail Merchant Saul, 57, Retail Merchant
8. Stone	Phoebe, now 23 Laurel, now 13	Milton, now 16 Blind *Age 3 months	Daphne, 49, Secretary Raymond, 52, Baker

*Time of diagnosis

Procedure and Instrumentation

Only after parents were approached by contact sources were they contacted by the researcher and, following an initial meeting to explain the study, the family's cooperation and participation were obtained. Parents provided permission to speak with school personnel and other resource people familiar with their family's circumstances.

Data collection consisted of direct observations and intensive interviews conducted in the homes of the eight families selected, in the schools of the children enrolled in a K - 12 setting, and in the homes or offices of resource people aware of each family's dynamics. Lofland and Lofland (1984) refer to

participant observation as a process in which a multi-sided relationship is established and sustained by a researcher in order to develop an understanding of the association. Over 200 hours were spent in the presence of family members, educators, and resource people within a five month period with a range of 18 to 34 contact hours per family. Bogdan and Biklen (1982) define intensive interviewing as guided conversation with a goal of eliciting from the subjects rich and detailed materials that may be used in qualitative analysis, and in which the natural setting is the direct source of data and the researcher is the key instrument. Questions emerged from an initial literature review, the researcher's own experience in her family of origin, observations, and the interviewing process as it unfolded. As the researcher observed family transactions and interviewed family members, patterns emerged in the spouse-spouse, parent-child, and sibling-sibling relationships across families. As the study unfolded, numerous insights were gained that were not anticipated.

Summary of identified patterns

1. The long duration of the marriages at the onset of diagnosis (5 to 18 years), with the exception of one participating family, appear indicative of the spouses' ability to remain in their marriages in the aftermath of diagnosis.
2. Early marriage with children at the onset along with a straitened economic situation appear to be factors in the dissolutions of one of the 8 marriages (the Edges) within two months of the completion of the researcher's interaction with the family.
3. All participating mothers report that their ability to cope with their special circumstances relies on outside employment and involvement.
4. Fathers demonstrate positive relationships with undiagnosed offspring, whereas conflictual relationships of fathers with diagnosed sons who are of normal intelligence are apparent. None of the fathers of diagnosed females express feelings of distance from their diagnosed daughters although they still appear to feel closer to their undiagnosed children.
5. Although the quality of the spouse-spouse relationships in this study appears to have remained quite stable over time, the quality of parent-child relationships has changed. Further, the younger ages of the children in two of the participating families may contribute to more positive over-all parent-child relationships than when these offspring reach adolescence.
6. Intergenerational parent-child relationships in some instances become parents to present relationships in that feelings of distance, affiliation, and

loyality in a parent's family of origin appear to have repeated themselves in some existing nuclear families.

7. Undiagnosed children demonstrate a sense of well-being when they share close relationships with both parents and when parents encourage independent behaviors in their diagnosed children.
8. At-risk parent-child patterns that were identified in the literature and/or are supported by this study include:
   a. the diagnosed child is seen as the family focus
   b. the mother is seen as overinvolved with the diagnosed child
   c. the undiagnosed offspring is seen as a reminder of what the diagnosed child can never be which appears to contribute to more intense feelings of guilt and chronic sorrow
   d. fathers spend much more time with their undiagnosed children than their diagnosed offspring
9. Most undiagnosed offspring say that they tend to keep intimate thoughts and feelings private.
10. Some undiagnosed siblings experience acute feelings of being different. They express chronic sorrow for their diagnosed sibling's shortcomings and their own related stigmatization.
11. The majority of undiagnosed siblings demonstrate extreme sensitivity to a diagnosed child's feelings. Some are said to over-identify with their diagnosed brother or sister.
12. Siblings talk of family fighting and distancing as a result of being placed in a acaregiver/disciplinarian role.
13. Role-confusion of two younger undiagnosed brothers who are close in age and who are members of two-child families is evident. These younger undiagnosed brothers express feelings of resentment for having to compensate and care for their older diagnosed siblings and resentment that their brothers require so much familily energy.
14. Most siblings profess acceptance of and loyalty toward their diagnosed brother or sister.
15. Family members do not express happy or positive thoughts when they discuss the future.

Unanticipated Insights

1. Undiagnosed siblings emphasize the normal aspects of their handicapped brother or sister more than their parents do.
2. Given 2 or more undiagnosed children in the family, the presence of a

handicapped child may contribute to somewhat exaggerated feelings of closeness or distance among the undiagnosed children.

3. The later in the disabled child's development that the diagnosis is made, the more devastating appears to be its effects on family members' adjustment.
4. Undiagnosed children in this study who are older than their diagnosed sibling, especially if they are members of a family with three or more children and there is a large age gap between them and their diagnosed sibling, are more likely to be reasonably well-adjusted and socially active.
5. Undiagnosed children in this study who are younger than the diagnosed child, closer in age, and are members of a two-child family tend to be on the fringe of social activity and to experience feelings of chronic sorrow regarding their diagnosed sibling.
6. Parents prefer specific diagnoses; they see labels as useful tools as they advocate for the best program placement for their diagnosed offspring. Conversely, professionals are described as hesitant to provide specific information about the diagnosis and available support resources.
7. Undiagnosed siblings are often curious enough about their brother's or sister's handicap to undertake personal research about it.
8. Few parents appear to realize that undiagnosed siblings need information and open communication about the disabled child's handicap so that the undiagnosed child himself or herself can understand and come to terms with the condition of their handicapped sibling.
9. In no case had a professional person interacted or communicated with an undiagnosed sibling at any length.
10. Undiagnosed siblings appear to feel hesitant to share their sorrow regarding their brother's or sister's handicap or their own stigmatization with other family members or their peers.
11. Adolescent undiagnosed siblings appear to be caught in a bind in which loyalty to a handicapped sibling contends with their need for peer acceptance.
12. Fathers' needs for information and communication about how to care for their handicapped offspring seem overlooked by professionals.

Research Implications

The place of undiagnosed siblings in handicapped families has been sorely neglected by researchers. Important substantive matters have not been examined. While handicapped families may demonstrate patterns that might be considered

dysfunctional in families without a disabled child, such patterns may be adaptive when considered in the context of the family's social, philosophical, and/or religious environment. What constitutes functional family transactions is not easily determined. Some questions arise nonetheless that include: 1. the importance of marital satisfaction for undiagnosed sibling adjustment, 2. the significance of differential parental treatment of offspring, 3. the degree of impact on adjustment as related to the identification and sense of responsibility with which the undiagnosed siblings relate to their handicapped brother or sister, and 4. the extent to which medical, educational, social, philosophical, and religious inputs contribute to or impair marital harmony and sibling adjustment.

It seems important to understand subsystem (spouse-spouse, parent-child, sibling-sibling) similarites and differences. Comparing and contrasting subsystem similarities and differences across different types of handicaps could contribute to a model of family coping styles in general, as well as handicap-specific family needs.

Subsequent ethnographic studies of handicapped families would be encouraged to use larger samples and focus on one subsystem of the family, one aspect of the family's psychosocial milieu, or on one type of analysis--e.g., internal or comparative. Control groups of families without a disabled child might be useful or confusing. If the contrasting transactions in handicapped versus nonhandicapped families lend insight into the value of differential professional and parental treatment of siblings, for example, then the use of controls might be beneficial. Although this study did not compare nonhandicapped and handicapped family transactional patterns, it did compare groups of lower and higher adjustment. Further study of these adjustment patterns (e.g., pre-birth marital integration as a major determinant of subsequent satisfaction) using larger samples appear warranted.

Long-term management of sibling adjustment challenges should guide further research efforts. Longitudinal studies that would follow the families from the onset of diagnosis of the handicapped child over a period of years would provide valuable information about the changes that occur in the undiagnosed sibling's circumstances over the lifespan. The care of a handicapped sibling often requires restructuring of role demands for all family members. Role confusion is evident among several of the participating undiagnosed siblings in the study; whether such confusion leads to greater risks or improved adaptation in adulthood would seem worthy of further study.

The voluntary nature of participating families may have biased the study (e.g., using families who may feel more comfortable discussing their handicapped situation). Studying single-parent handicapped families might present a quite different portrayal of coping inasmuch as stress levels in such families would likely be exacerbated.

Implications for Practice

Extended family, friends, and professionals may enhance undiagnosed sibling responses to their diagnosed brothers and sisters by providing acceptance, understanding, support, and information (Hanold & Davis, 1988). Bubolz and Whiren (1984) recommend that the total family unit be considered in the development of a plan for a handicapped child to insure that the decisions made are likely to result in the greatest benefits and least costs to all members of the family.

Lack of contact with handicapped families encourages a belief that dysfunction is a normative pattern in families with a handicapped member (Crnic, Friedrich & Greenberg, 1983). Most of the families in this study appear to cope reasonably well and to be involved in healthy family transactions. Most of the families had resources readily accessible to them initially in order to adapt to their challenging circumstances. Yet, as Longo and Bond (1984) suggest: "Not only do families who are functioning adequately need support, professionals also need contact with them in order to enlarge their repertoire of basic assumptions."

Parent-child transactions often fail to assist the offspring in a handicapped family to consolidate an adequate sense of autonomy or competence. These transactions might serve as the focus of family therapy (Ziegler, 1982). However, an adaptive response to those transactions might be better achieved via a therapeutic atmosphere that emphasizes assets, strengths, and healthiness rather than deficits (Wilcoxon, 1985). Establishing realistic parental expectations of both undiagnosed and handicapped children needs to be stressed along with open communication of feelings.

Zeitlin, Williamson, and Rosenblatt (1987) provide an array of available options for working with handicapped families: parent (both mother and father) support groups, workshops on topical areas of interest, respite care, and referral to community resources. For undiagnosed siblings in particular, discussion groups are reported to be an important mechanism for gaining information and sharing experiences (Lobato, 1983). How to tell friends about their handicapped sibling, how to cope with teasing from peers, and how to respond to parents' expectations would appear to be important topics of discussion in these sibling groups. Role confusion often experienced by siblings might be another issue dealt with in these groups as well as planning for adult life. Providing information about the causes of the specific disability would be a valuable service.

Stewart (1978) says that an undiagnosed sibling's involvement in family therapy sessions, visiting the diagnosed sibling's school, being able to ask questions, and visiting the diagnosed brother or sister in the hospital are important in assisting

undiagnosed siblings to feel included and to understand the treatment and procedures that the handicapped child undergoes. Assisting an undiagnosed offspring to explore the possible impact of a handicapped sibling on future marriage and family plans might relieve some apprehension.

The professional's task, it should be emphasized, is as much to listen to the complaints and fears of a handicapped family as to provide information. Indeed, fears must be exposed and dealt with before useful information might be absorbed. Collaborative meetings with the family, the therapist, and medical and school personnel regarding the entire family's situation seem conducive to undiagnosed sibling adjustment (Hanold & Davis, 1988).

The professional who is working with a handicapped family would be wise to indicate to its members that she or he realizes that their situation is a challenging one. Throughout the helping process, the professional might act as "a safe repository" for the family's pain and discomfort. Although undiagnosed siblings need to acknowledge that the handicap exists, they need not become preoccupied with it. In the lives of a population of children whose needs have for too long been forgotten, informed and sensitive professionals might provide comfort, understanding, and hope.

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